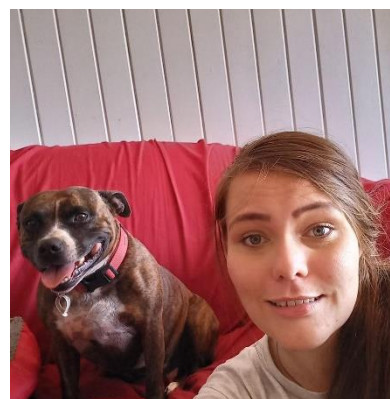




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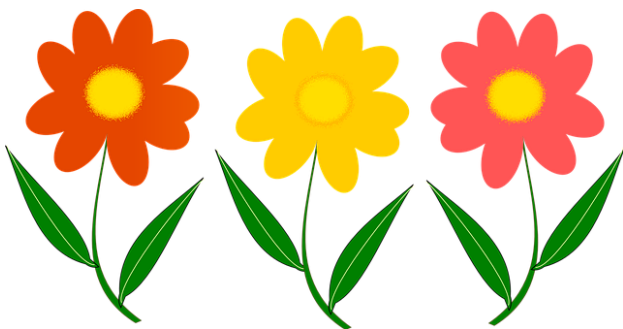


Meet our new committee members on page 10-13

See what Edna has been up to on page 6



PRESIDENT'S REPORT



Well, 2021, here we are. I trust everyone had a happy, safe Christmas and New Year. Hopefully this year will be an improvement on the last.

In November we held our Annual General Meeting where it was time to elect a new committee. I was delighted to be elected President again and we have Maree as Secretary, Michael as Vice President, Maja as Treasurer and our general committee members Abbie, Tanya, Melo, Hilary, Georgie and Margaret. We also farewelled Niki Harrison, Anna Uther, John Jonker and Pieta Harris. Thank you all for volunteering your time to AusDoCC.

Once again, as we head into this year things seem a bit uncertain. We have a few new Zoom activities, along with our second Adults with ACC conference, "My People," in June. We are looking forward to the possibility of having a few face-to-face meet ups.

An AusDoCC membership is a one off payment of \$20 per person. Members have extra benefits, as well as assisting us to support families with a DCC like yours and mine. Membership application forms can be found on the website at www.ausdoacc.org.au Please follow this link and click on the orange "Join AusDoCC" icon.

Please head to our Facebook groups to introduce yourselves, share your stories, add a photo or ask a question. We have two groups, the main group which is called **Ausdoacc - Australian Disorders of the Corpus Callosum** and also our Adults group called **Australian and New Zealand ACC Adults**.

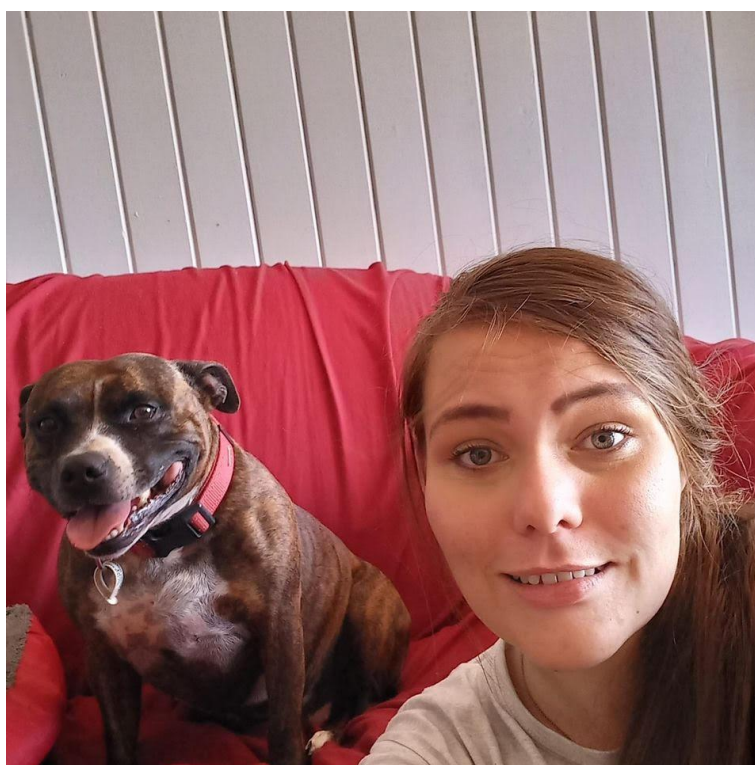
Peace 🕊
Tina.



JADE'S STORY

My name is Jade, I'm a twenty-three year old partial DCCer who considers herself a "Bogan by the ocean", up here in sunny Central Queensland. Quite unlike Jesus, I was born kicking, screaming, and one month premature to two bewildered first-time parents in their late thirties. That first month, from what I have been told, was scary. I was in a humidi-crib for a month with drips and feeding tubes galore. By May, I was fit enough to leave the hospital. I hit all the usual milestones except crawling. I went from bum-scooting to swaggering like Mick Jagger, so I'm told.

Back in 1997 there were no ultrasound tests for DCC and as I showed limited symptoms in school, I was never scanned (until adulthood). As a kid, I was academically rather successful. Socially I struggled yet managed to find a group of friends who also got picked last for team sports and couldn't tie up skipping ropes into neat little bundles. High school was a breeze. I was always nerdy and P.E. was optional so my only real hurdle was social skills (and the almighty cannonball that is puberty). Slowly but surely, through much trial and error and many, many hours in theatre classes analyzing and deconstructing why people do and say what they do, I developed a robust social life. I was voted "Best friend to everyone" at graduation. An accolade I consider to be the height of my career thus far...



But that might be because adulthood has been my biggest struggle. Not bike riding nor school bullies or algebra but independent living. I moved to Brisbane to study at university as soon as I could (desperate to leave my tiny town) and loved it. But my perfectionism and severely nervous disposition led to being hospitalized in 2015 with severe Anorexia Nervosa. Since then, I have been in and out of psychiatric wards with different anxiety-related mental illnesses and have been prescribed more gnarly drugs LEGALLY than I could have ever experimented with at a music festival.



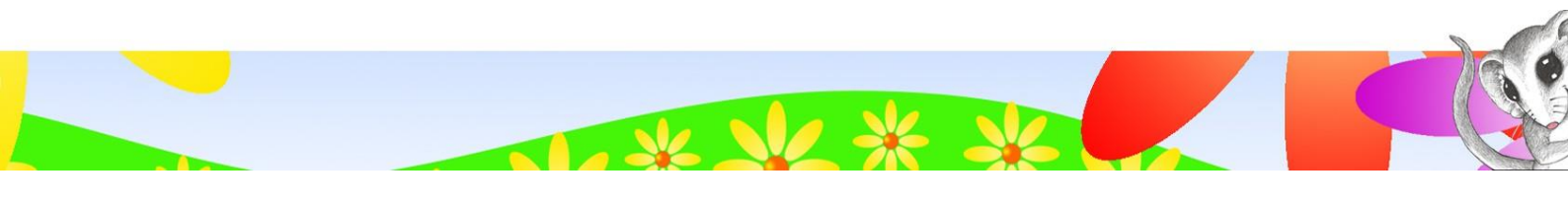
One disorder I developed is called Conversion Disorder. It can present similarly to a Tourette's attack; jerky, repetitive movements, grunts or speech, again and again and again. Sometimes this can even look like a seizure (neurologically however, it is very different to actual seizures). This prompted us to push my psychiatrist for an MRI to be certain that everything was alright, biologically, with my noggin. It was! Kinda...

So, at the age of twenty-one I was diagnosed with partial DCC and have been learning to cope with it ever since. I now know WHY I get so anxious, even after so much therapy. I know what sensory processing issues I have like; bright lights, vibrant colours, certain textures like velvet and loud sounds. I now prioritize meditation or "low stimulus" time, as a cool down from or before a big event. But most importantly? My parents now have an answer as to why their seemingly normal only child went so ballistic when thrust into adulthood. It was NOTHING they did or could have prevented. I have the most loving and supportive parents in the world, and I cannot sing their praises enough. So, to the parents who are raising a kid with a DCC, please know there is some kind of hope. They will not be "normal", so get rid of all your expectations now but never underestimate the work you're putting into raising a child with higher needs. They appreciate and love you. Even if they can't tell you themselves or are currently a sack of hormones and hatred.



I'm now living back in my hometown, single and with my Mum (who acts as my carer I suppose) and our recently adopted Staffy. I work part-time as a commercial cleaner and help pay the mortgage (partly a financial need but mostly to give me a sense of autonomy) and have enough friends to keep my weekends busy. So no, it is not what I pictured life would be like after graduation. It is not what my parents thought their fiercely independent child would be doing. But there is nothing wrong with a simple life lived well. Besides, why do your own laundry when Mum can do it for you?

All the best,
Jade



VALE ANNE COURTNEY – Foundation Member

We were sorry to learn of the death of Anne Courtney in December after a long battle with illness. Anne was a stalwart and a strong AusDoCC supporter.



She wrote a book about her son, Bill's, life with ACC, called 'Where there's a Will.' Bill Courtney is one of our highly valued adult members and one of the first to be diagnosed with ACC in Victoria. Anne will be sorely missed by many people. We extend our condolences to Bill and his family.



WELCOME TO THE WORLD

Eliza Judith Blanchard

20/04/2020

2.596 kg

Eliza was born in Melbourne and has grown into such a happy, spunky little lady. She is hitting all her milestones and loves to wave, dance and explore the outdoors. She is a dual New Zealand and Canadian citizen, and her extended family can't wait to meet her once travel is allowed. Eliza's diagnosis is hypoplasia of the corpus callosum due to a lipoma.



Asher Philippe Hall

3/1/2021

2.83 kg

Born 40 weeks & 4 days by induction. At 24-27 weeks we were offered multiple terminations and we decided to take the risk and are now blessed with a perfect miracle. He has complete ACC and a really cute, webbed toe, he is the most handsome little boy and we are so proud.



WELCOME TO THE WORLD

Evie Hayter

3rd April 2020

weight 3460grams

CACC

Evie loves to watch birds and has a keen ability to find them in any situation. She is on track with her development and quite social. We are blessed with our "little possum".



Cayden

09/11/20

8lb 7oz

Cayden was born with C-ACC among a few other things. He is very smart and currently shows no signs of any issues related to C-ACC... He is such a happy boy. Currently 11 weeks 5 days old.



EDNA AND THE MYSTERY VISITOR

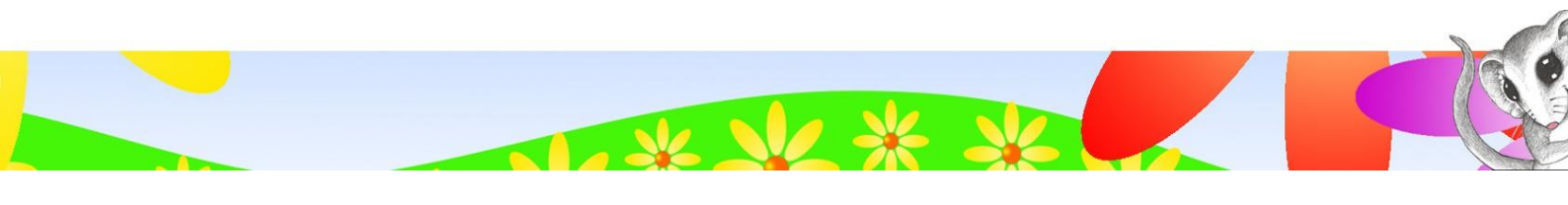
Well... I'm getting very, very excited because Mum and Dad told me we have a special mystery visitor coming to stay.

Right now she can't be coming to stay because we are being very careful not to catch the coronavirus. I can wash my hands for 20 seconds and I sing, "Happy birthday to me," even though it is not my birthday. I can sing it two times in 20 seconds.

Sometimes I go and make my hands dirty again so that I can sing it and wash them. I don't want anyone to forget my birthday so that is my little reminder to everyone. Cool huh? You should try it.



My birthday is on July 2. I hope they don't forget. I wonder who the mystery visitor will be?



WORDSEARCH

What's In The Garden

X	S	O	T	A	D	M	N	B	B	V	G	H	F	R
Q	H	P	F	Y	I	O	L	R	L	E	D	O	L	E
Z	N	G	I	N	Z	U	T	O	O	R	T	E	E	B
N	K	E	T	N	E	V	I	A	B	C	M	N	L	M
R	D	K	L	B	A	N	N	O	T	B	P	D	Z	U
K	O	A	E	M	I	C	R	T	S	O	I	I	F	C
M	A	R	I	H	I	O	H	O	T	Y	P	F	D	U
A	R	L	C	S	N	M	J	R	R	T	L	F	C	C
Y	E	C	Y	I	Y	G	E	R	A	N	I	U	M	P
D	U	P	A	P	S	Y	Y	A	W	F	C	L	D	A
Z	S	H	T	S	I	R	I	C	B	A	J	I	V	R
N	A	R	L	E	C	B	N	H	E	X	H	R	B	S
P	E	C	C	W	E	J	V	H	R	C	K	O	S	L
O	T	A	M	O	T	W	H	Q	R	M	J	S	Y	E
O	N	I	O	N	G	C	S	O	Y	L	C	E	U	Y

Can you find these words in the grid above?
They may be forward, backwards, up, down or across. Good luck!

BEETROOT
BLUEBERRY
BORONIA
CARROT
CORN
CUCUMBER
DAISY
GERANIUM
IRIS
MINT

ONION
ORCHID
PARSLEY
POTATO
ROSE
SPINACH
STRAWBERRY
SWEETPEA
TOMATO
ZUCCHINI

If you would like to send me your favourite photo, story or poem about Summer, please email it to editor@ausdocc.org.au before 30th April 2021 for inclusion in the next newsletter and please don't forget to put your name on it.



NEW AUSDOCC COMMITTEE 2020-2021



Welcome to the new volunteer committee members Georgie and Melo (NSW), Margaret (SA) and Hilary (Qld). They will join Tina & Maja (WA), Tanya (NSW), Michael (Qld) and Abbie & Maree (Vic). We have quite a spread around the country at the moment which is great for us to represent our AusDoCC community. We also have some amazing support from our volunteer supporters in the AusDoCC Diamond Mine. If you would like to become an AusDoCC Diamond and volunteer from time to time or just be a 'friend' to AusDoCC you can join here.

<https://www.facebook.com/groups/986410298384706>

We were sad to farewell Niki, Pieta, Anna and John who have all been long time Committee members and given much blood sweat and tears to make and grow our AusDoCC family to be where it is today. We hope they are not strangers and are enjoying a well earned break. Thank you to you all for the wonderful commitment you have made to our grassroots, volunteer organisation.

We are very proud of what we can offer. In this issue we have included a small hand out that is given to new committee members as an outline of some of the things we do as an operational organisation. It may shed some light on some areas and we are always open to new ideas, projects and support.



WELCOME TO NEW COMMITTEE – TIPS

NAME	WHAT IS IT?	WHY?
BrainSells	The AusDoCC Shop	Fundraising and sharing AusDoCC merchandise.
Committee roles	Area of responsibility	Each Committee member has at least one role in an area they wish to pursue. Put together they make the whole elephant
Committee tasks	Small tasks for everyone	To get a good range of feedback or ideas on a topic. These have deadlines
Conference Connections [year]	Our biggest event held on alternate years to the NODCC	Gathers adults with DCC, families, professionals together for presentations and workshops. Biennial event. (Next is 2022 in Melb)
Connecting Up	Quarterly Newsletter	Share information and knowledge with DCC community and beyond.
DropBox	Cloud file storage system	To store documents for committee to access via the internet
Edna the fat tailed dunnart	Our mascot	For kids (and adults) to identify with. She has no corpus callosum.
Face to Face	Annual Committee meeting in Melbourne	Annual get together for planning and reviewing. Currently some grant support.
Facebook	Social media platform	Several private groups for interaction and sharing information One Facebook Page as a public face and one public research page
Google Docs	Platform to create text documents & spreadsheets	Easy access for all. Can be shared with others and worked on simultaneously
Kit Kat	A break	Sometimes major life incidents interrupt life, e.g. death, divorce, illness, accidents. Take a Kit Kat
Model Rules	Rules that govern AusDoCC	Complies with Incorporations Act 2012
Monthly Meetings	Held 2 nd Tuesday of each month at night.	Committee decision making, planning and discussion. All operations of AusDoCC
Policy & Procedures	Operations manual	Living document composed by AusDoCC to guide all our operations
Proposal Form	Application for projects	Form to outline your fabulous ideas and plans.
Undertaking Form	Signed declaration for all committee members	Required by Model Rules for confidentiality, compliance and responsibility to AusDoCC
Strategic Plan	Our aims and plans	Reference document guiding all we do
Zoom	Visual communications platform	To connect online when face to face gatherings are impossible or too expensive



"NOW TURN YOUR ATTENTION TO ITEM NO. 167 ON YOUR AGENDA ..."

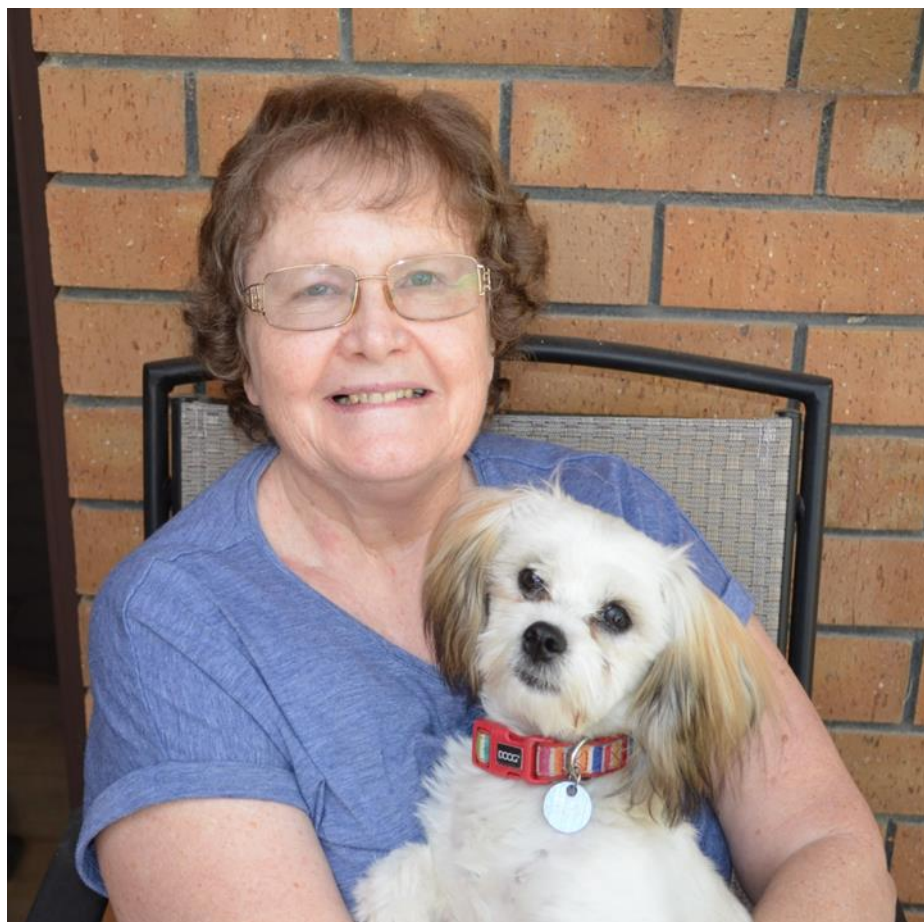


NEW COMMITTEE MEMBER: MARGARET KRUTLI

Margaret has Complete ACC, which was discovered when she was 40. She was been married to Chris for over 40 years & has 2 adult children. They live in the southern suburbs of Adelaide. Margaret joined the AusDoCC in 2018 & the Perth Conference was her first. She joined the Committee to help adults with ACC & parents, who have children with ACC, in South Australia, connect with each other.

Margaret worked in Small Business, involving Customer Service & Clerical work. She has been a full-time mum in her children's growing years and volunteered in various organisations for 30 years.

Meet Ruby, her fur baby.



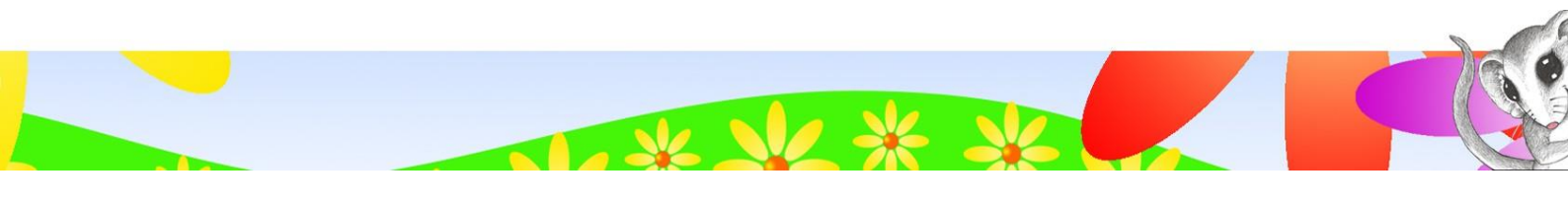
NEW COMMITTEE MEMBER: HILARY BUSTILLO

Hilary is a mum of 3, and her youngest child Karina is 5 years old with Complete Agenesis of the Corpus Callosum. She has been a member of AusDoCC since Karina was born, is motivated to contribute to building community connections and practical supports for people with Disorders of the Corpus Callosum. Prior to joining the committee this year, Hilary has been involved with fundraising for AusdoCC conferences by completing a stair running challenge and has been a regular participant in local area AusdoCC meet up's.



Hilary is a nurse in Queensland Health and specialises in Community and Aged care nursing. She currently works as a Clinical Nurse in a major Brisbane Hospital and is involved in geriatric assessment and case management for community supports and services. During the turbulent year of 2020, she has branched out of her comfort zone, and assisted in a local fever clinic with COVID testing.

Hilary enjoys weightlifting and plans on entering a bench press powerlifting competition in the new year, COVID permitting.



NEW COMMITTEE MEMBER: MELO KALEMKERIDIS

Melo with his daughter Victoria.



NEW COMMITTEE MEMBER: GEORGIE LAMB

Georgie Lamb lives in Bathurst New South Wales and was diagnosed with complete ACC at the age of 17. She has learning difficulties, balance and co-ordination issues, spacial awareness, social anxiety and depression.

Georgie has her cert 3 in Education Support (Teacher's Aide) and gained her Black Belt in Karate in 2012.

Georgie has ongoing support with disability and mental health services in town funded by the NDIS.



NDIS SUPPORTS FOR DCC

Hi everyone. I hope you're all recovering and relaxing after the hectic and weird year we have had. This can be a happy time of the year but there are also many who struggle so I hope you can find your happy place over the festive season and summer.

I want to float an idea. We will talk more about it when the year takes shape but wanted to introduce you to the idea to think about.

We'd like to get a small group of people together to work on producing some information to help people with a DCC negotiate the NDIS. We would try to work out the most important things to mention when trying to become an NDIS participant as well as how to get good support and what sorts of things to ask for in a plan. Perhaps we could add it to our Ten Top Tips series of AusDoCC resources (see www.ausdocc.org.au and click on the Resources tab.)

Some people find it very hard to deal with NDIS because everyone with a DCC is so different and hardly anyone you speak with has ever heard of the condition. If we could work as a group and put some peer support guidelines together, it would be helpful.

If you are interested in being part of a group like this, please message me on Facebook or email info@ausdocc.org.au. Look forward to hearing from you.

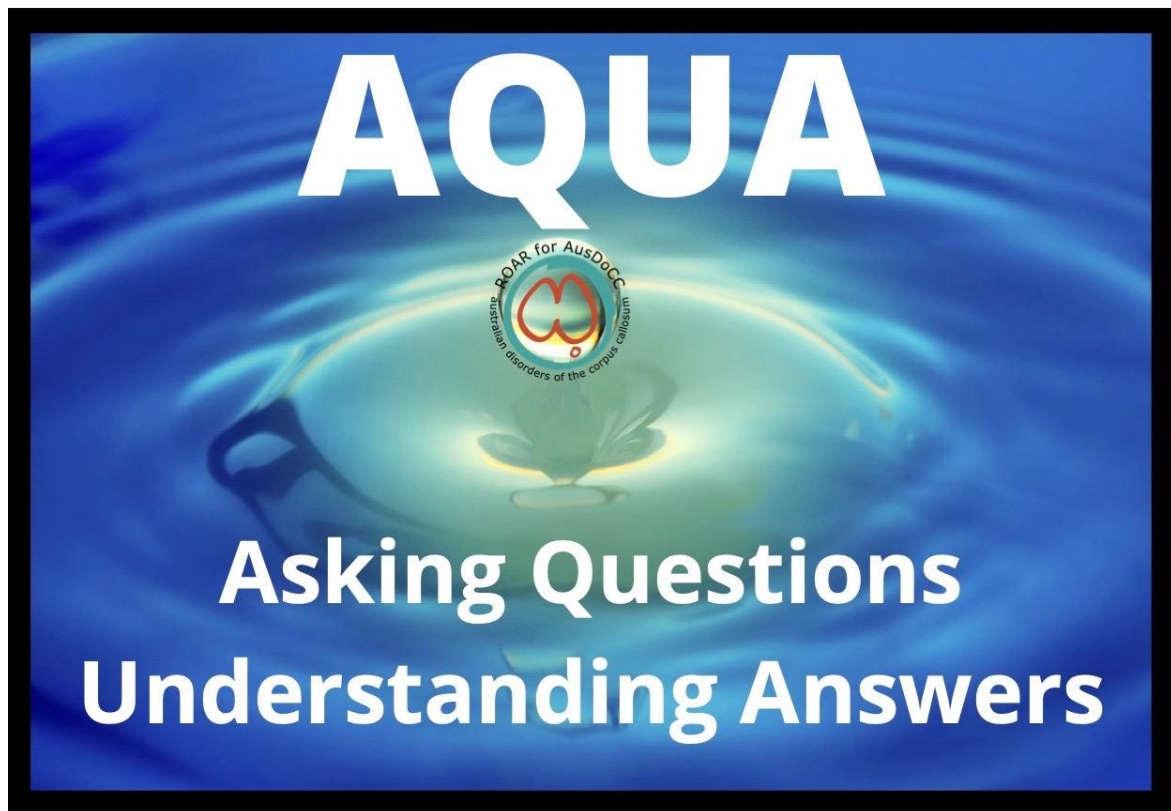
Maree Maxfield (secretary)



Funded by the National Disability Insurance Agency



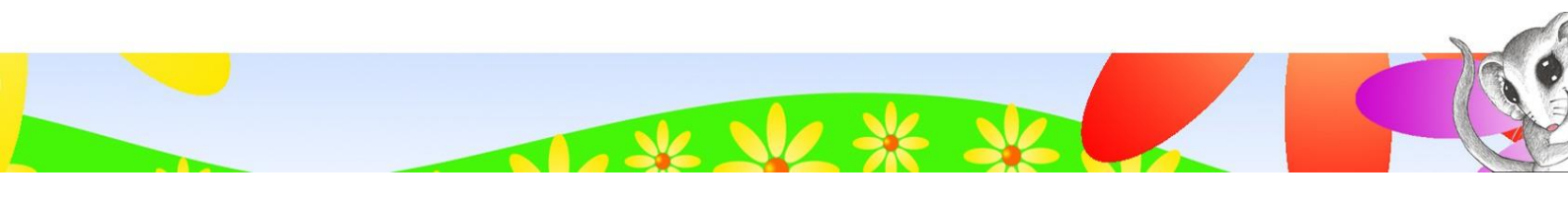
COMING SOON TO AUSDOCC – AQUA



We have had our first pilot session of AQUA (Asking Questions, Understanding Answers). It was a session about Relationships with Dr Natasha Alexander. To our delight, Natasha was in her usual top form and conducted a very heartwarming and informative session for adults with ACC. Regular AQUA sessions will start in February 2021, beginning with adults with ACC.

An AQUA session begins with a short presentation about a particular topic related to DCC, followed by the opportunity to ask questions about the topic. People can submit questions prior to the session or during the session.

A timetable for the year will be available in February. Once the program is in full swing, we will begin to explore sessions for parents and teens. AQUA is funded by an **Information, Linkages and Capacity Building** grant from the NDIA.



AUSDOCC QUEENSLAND FAMILY FUN DAY

Saturday the 6th March at 12:30 pm

Clem Jones Centre

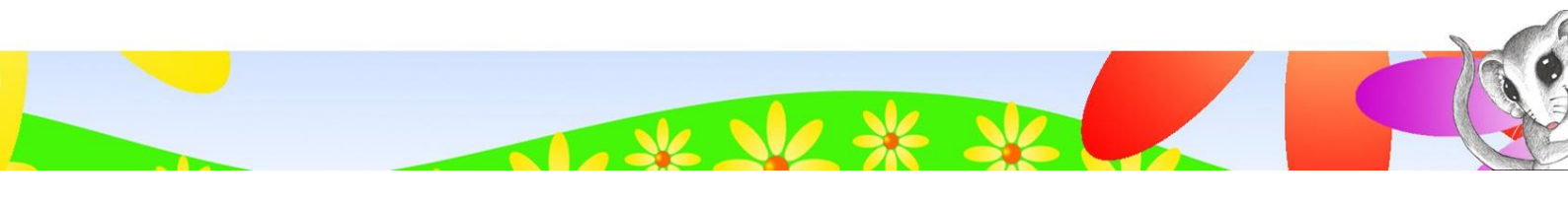
53 Zahel Street Carina Qld

Come and join our family fun day at the Clem Jones Swim Centre on the Southside of Brisbane.

We will be having a BBQ lunch and face painting.

Numbers are limited so please RSVP!

hilarylouise@y7mail.com



IMPORTANT DATES TO STICK IN YOUR DIARY



2021

6th March

Queensland Meet up (See Flyer Above)

18th - 20th June

Adult's Conference

2nd July

Awareness Day

2022

April

AusDOCC Conference



BRAIN SELLS SHOP



Brain Sells

The AusDoCC Shop

www.ausdocc.org.au/shop

ausDoCC

australian disorders of the corpus callosum



You can order AusDoCC merchandise at www.ausdocc.org.au/shop



MEET THE AUSDOCC COMMITTEE



Kristina Coburn

AusDoCC President, Social Media Officer



Michael Shanahan

AusDoCC Vice President, Research Officer



Maree Maxfield

AusDoCC Secretary, Website Officer



Maja Palacios

AusDoCC Treasurer, Design Officer



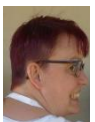
Abbie Kinniburgh

Adult Programs Officer



Tanya Smith

Volunteer's Coordinator



Georgie Lamb



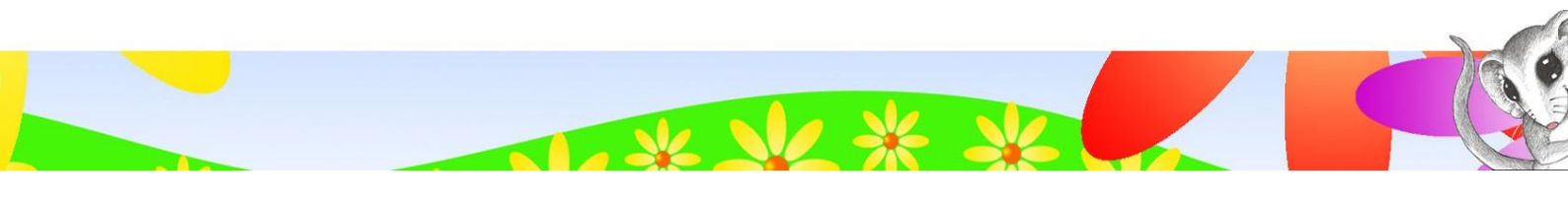
Melo Kalemkeridis



Margaret Krutli



Hilary Bustillo



NOTE FROM THE EDITOR

Thanks again to everyone who contributed articles to this edition of the newsletter and to the team behind the scenes who help to present it. I would love to hear from you if you would like to share your family story. Your experience may be helpful or inspiring for others dealing with a disorder of the corpus callosum.

If you have a story or photos that you would like to share in the next edition, please email to

editor@ausdocc.org.au

by 20th April 2021.

Enjoy reading

Cheers Margie



For more information about AusDoCC
visit www.ausdocc.org.au

Facebook support group -
<https://www.facebook.com/groups/ausdocc>

Facebook support groups ADULTS –
<https://www.facebook.com/groups/355338714574689/?fref=ts>

Facebook page – <https://www.facebook.com/AusDoccInc>

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